



Requiring Newborn Screening for Critical Congenital Heart Defects

Proposed Legislation for Montana

Support to date:

- The American Heart Association
- The American Stroke Association
- The American College of Cardiology
- The American Academy of Pediatrics
- Health & Human Services, NHBLI, CDC
- Intermountain Healing Hearts
- Mayo
- Holy Cross Hospital
- March of Dimes
- 100% of Montana Pediatric Cardiologists
- Mended Hearts organization
- Montana Heart Institute
- Shodair Hospital
- Dennis Dietrich, MD (Neurologist) Gt Falls
- Richard Paustian, MD (Cardiologist) Helena

What it Does

- Requires all newborns in Montana to be screened for critical congenital heart defects (CCHD) prior to being discharged from the hospital or birthing facility.
- The test, pulse oximetry, or "pulse ox", consists of sensors placed on a baby's hand and foot to check blood oxygen levels. If their levels are too low, additional tests are conducted to detect critical or possibly life-threatening heart defects that might otherwise be missed.
- Each screening takes 1 to 5 minutes and is administered in the hospital using equipment that is standard in most hospitals. Pulse ox would be one of the least invasive tests given in hospitals while providing time-sensitive data for diagnosis and treatment purposes.

Why it is Needed

- Congenital heart defects are a problem with the heart's structure and/or function which is present at birth.
- Nearly 1 in 3 infants who die from birth defects has a heart defect. Congenital heart defects are about 60 times more prevalent than childhood cancers.
- Children with CCHD have life-threatening symptoms that require intervention, such as surgery, in the first few hours, days or months of life.
- Research suggests wider use of pulse oximetry screening could help identify more than 90 percent of heart defects.

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Representative Doug Coffin,

Chief Sponsor

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- Nearly 1 in 3 infants who die from birth defects has a heart defect. Congenital heart defects are about 60 times more prevalent than childhood cancers.
- Children with CCHD have life-threatening symptoms that require intervention, such as surgery, in the first few hours, days or months of life.
- Research suggests wider use of pulse oximetry screening could help identify more than 90 percent of heart defects.
- Cost estimates for CCHD screening are less than \$5 per infant, a tiny expense to save lives.
- Several states such as New Jersey, Maryland, Indiana, West Virginia and Tennessee have successfully added pulse ox to their standard/universal newborn screening battery of tests with life-saving results.

Talking Points

- Congenital heart defects are the leading cause of birth-defect related deaths in the United States.
- By using a test called pulse oximetry, low oxygen levels in the blood can be readily detected—a significant indicator of heart issues in babies.
- The U.S. Secretary of Health and Human Services has suggested that critical congenital heart defects screening be added to the “Recommended Uniform Screening Panel” for newborns before they are released from a hospital or birthing facility.
- This bill simply adds pulse oximetry screening to the current screening panel in Montana.
- **Support newborn screening (Pulse Ox) and help ensure newborns are screened for critical congenital heart defects so those diagnosed may live longer and fuller lives.**

March 18, 2013
Rep. Doug Coffin
C/O Montana House of Representatives
P.O. Box 200400
Helena, MT 59620-0400

Dear Representative Coffin:

I am a pediatric cardiologist practicing in Montana. Thank you for introducing HB 601 which would require birthing centers in Montana to perform a newborn screening test for critical congenital heart disease (CCHD). Hospitals in Western Montana already perform this test. I believe all birthing centers in the state should perform this test. HB 601 is an essential step to ensuring every child born in Montana is afforded the opportunity for a long and healthy life.

Congenital heart disease is the most common birth defect. The term "critical congenital heart disease" includes more serious forms of CHD. CCHD affects 4 per 1000 babies born each year and is leading cause of death for babies born with birth defects. In addition to death, failing to detect critical congenital heart disease in time can cause cognitive and developmental delay, leading to life-long medical care.

Pulse oximetry has been found to be an effective screening mechanism for CCHD in the newborn nursery. Pulse oximetry is a quick, inexpensive and painless test and usually takes less than 4 minutes to perform. The cost of pulse oximetry screening using a reusable probe is approximately 1 dollar, comparable to that of a diaper change.

In September 2011, pulse oximetry screening for CCHD was added to the recommended uniform screening panel for all newborns. Ten states have already required newborn screening for CCHD, and 23 states are currently considering legislation to make screening for CCHD available to all newborns within their state. At least four states are pursuing regulations to mandate screening of the infants in their states and to ensure that access to this screening test is equitable throughout the state. HB 601 will ensure that all infants have equal access to this quick, painless and low-cost test throughout our state. Enactment of this measure will guarantee that outcomes for infants born with CCHD will be improved.

Please urge the members of the House Human Services Committee to support HB 601. This bill establishes a common sense approach to tackling a critical children's health issue.

Sincerely,
James Wise Wiggins, Jr., M.D., F.A.C.C.
St. Vincent Healthcare Pediatric Cardiology
1232 N 30th, Suite 300
Billings, MT 59101-0139

Representative Doug Coffin
c/o Montana House of Representatives
PO Box 200400
Helena, MT 59620-0400

March 7th, 2013

Dear Representative Coffin,

On behalf of Shodair Hospital we thank you for sponsoring legislation to ensure statewide newborn screening for critical congenital heart disease (CCHD). The legislation (currently LC1088) has a minimal fiscal impact and is an essential step to ensuring every child born in the state of Montana is afforded the opportunity for a long and health.

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In September 2011, pulse oximetry screening for CCHD was added to the recommended uniform screening panel for all newborns. Currently, a number of states have either passed legislation, are considering legislation, or are pursuing regulations to mandate screening of the infants in their states and to ensure that access to this screening test is equitable throughout the state. At Children's National, we have successfully worked with hospitals, state departments of health and foreign countries to implement CCHD screening programs in their nurseries.

Some hospitals in the state of Montana have chosen to implement CCHD screening programs in their organizations because they felt that it was simply the right thing to do, and realize that it is quickly becoming a standard of practice. Through this legislation, it will be ensured that all infants have equal access to this quick, painless and low-cost test throughout the state, and that the outcomes of our infants born with CCHD will be improved.

Again,t we respectfully request that you support congenital heart defect screening for newborns (LC1088). If passed, this act establishes a common sense approach to tackling a critical child health issue. Thank you for your attention to this urgent matter.

Sincerely,
Jack Casey
Jane Doe

CC: Cliff Christian, American Heart Association

CCHD Screening Legislation has passed and being implemented in these states:

3/21/13

Maryland
New Jersey
Indiana

New Hampshire
Connecticut
California

Tennessee
West Virginia

South Dakota
Virginia – By executive order

States with Current Introduced CCHD Screening Legislation

State	Bill	Most Recent Action	Fiscal	Effect Date
Oregon	SB 172	3/5/13 – House Health Care committee	--	Immediately upon passage
Nevada	SB 92	3/19/13 - Senate Health and Human Services Amended	\$8,500 in 2013-14 for regulation	
Hawaii	SB 1136	1/24/13 – referred to Senate Health and Senate Ways and Means committees	--	January 1, 2014
North Dakota	SB 2172	on House Floor calendar for 3/21/13	--	
Nebraska	LB 225	2/26/13 – Placed on Final Reading	\$16,000 for Educational materials, etc	
Minnesota	SF 473 HF 483	3/18/13 – Senate Committee on Judiciary 3/18/13 – Health and Human Services	--	
Oklahoma	HB 1347	3/13/13 – Senate Health and Human Services	--	July 1, 2013
Texas	HB 740	3/13/13 – Pending Public Health Committee	--	September 1, 2013
Iowa	SSB 1001	3/6/13 – Human Resources committee	--	October 1, 2013
Illinois	HB 2661	3/13/13 – House floor, second reading	--	
South Carolina	SB 341	2/6/13 – Referred to Senate Medical Affairs Committee	--	
North Carolina	HB 105	3/5/13 – Referred to Senate Committee on Rules and Operations	--	
New York	SB 270	January – Health committee – probably dead	--	180 days after passage
Massachusetts	S 1008	1/22/13 – Joint committee on Public Health	--	
Maine	LD 460	2/14/13 – Health and Human Services	Not yet determined	Immediately upon passage
Missouri	SB 230	Scheduled for Senate floor on 3/22/13	NVD	
Ohio	SB 4	3/20/13 - Sent to House	NVD	
Florida	SB 124	3/7/13 – Appropriations Subcommittee on Health and Human Services	Fiscal note not found	July 1, 2013
Utah	HB 276	3/19/13- Has passed both the House and Senate – now enrolled to Printing	\$8,000 in FY 2014	
Arkansas	HB 1468	3/18/13 – sent to Senate – Public Health, Welfare	NVD	



